Approved

Vermont Advisory Board for Children and Youth
With Special Mental Health Needs

September 8, 2006
Weeks, Waterbury Complex
12:00-3:00

Present: *Guy Wood, Ted Tighe, Jo-Anne Unruh, Kreig Pinkham, Jeff McKee*
Absent: Carla Brisson, Julie Welkowitz,
Guests: *Alice Maynard, Richard Cate, Steve Gold, Sharon Moffatt, Patrick Flood, Theresa Wood, Scott Johnson, Kim Keiser, Clare McFadden, Claire Bruno*

I. Board Business

- Adjustments to the agenda were made.
- July 25 minutes; tabled.
- Board appointments: Alice reported that Sherry Nelson has resigned. We will need a second parent nominee for 2006. Since we have still not received the paperwork from the second potential advocate, we will pursue a different person. After discussion, it was decided to proceed with the nominees we have for Guy's position and with a request to the DCF Commissioner once we have this 2005 position filled for a DCF representative to meet routinely with the Board to provide the same level of knowledge as the mental health and education representatives.
- Brief review of the details for the October 6 meeting. We will not know how many people will be attending until very close to the meeting date.

II. Autism

Clare McFadden (DAIL Autism Specialist) and Claire Bruno (DOE Autism Consultant) presented a brief summary of the findings of the recent white paper on Vermont's current population data, gaps in services, and recommendations with an update on steps taken since the paper's publication. [See attached.] Additional points made during discussion by meeting participants:

- Rate of diagnosis is up 17% nationally; up 20% in Vermont. Vermont data presented here is conservative; it does not include any youth on 504 plans.
- There is some debate about the outcomes of "intensive early intervention" services. The National Research Council asserts that 25 hours/week of intensive early intervention services from age 1 to 5 could result in significant improvements in school functioning for approximately 50% of youth with autism. We need to work to achieve consensus on definition of "intensive early intervention" services for Vermont.
- There is a clear need to expand training to professional staff and to parents; there is also a strong response to the initial training offerings.
- Cate: The state needs a more coordinated approach to service provision. We need a model and a mechanism to disseminate it within one year (6 months to identify current resources and 6 months to plan). He asked this Board to identify a small group of people to have this discussion and write the plan. With virtual regional centers, families and professionals could:
  1. get a list of experts who can accurately diagnose this condition;
  2. understand the services available regionally and statewide that are based on researched best practices; and
  3. get consistent answers to their questions.

- Debate whether to have an autism registry through legislation. Legislation is desirable to get maximum participation by the medical community. However, it could become very political if legislation is inserted.
- Moffatt: VDH has a registry that we could build on; it is currently being used for Chronic Disease and Immunization and could be easily added on to. A major advantage is that health care and school nurses are already using it. In addition, VCHP out of UVM has taken on different projects (*e.g.*, ADHD). They could pull together a team of professional people to generate what research has verified as best practices. Additional resources include staff from CAFU and the Designated Agencies; Jodi Brakeley, MD (pediatrician) of Cornerstone who connects pediatricians and schools; and Carol Hassler, MD (VDH's Children with Special Health Needs).
- Wood: DAIL has been determined as the lead department for developmental disabilities. However, there are definite limitations to the amount of funding available within DS to take on a new responsibility and this population can be both high needs and high cost. The current numbers cited do not count the approximately 200 children currently receiving Personal Care funding. It is possible that we could provide more training to PCA staff and to families; this might result in less need for PCA funding which could then be applied to families whose child has autism. PCA funding grew from $13 million to $20 in the last 18 months. With more attention to training and to outcomes, we might improve the benefits from this service strategy. It would have to be a voluntary option to the family because EPSDT is mandatory; barriers to accomplish this adjustment are probably internal to Vermont. If we agree on early intensive services, we must gather data on the outcomes.
- McKee: We need to assure a common message about what is needed and adequate training for staff and families. Once we have that message, families will demand to receive appropriate services and supports.
- McFadden: These options could meet the needs of many families. Nevertheless, there will still be families whose children have very high needs.
- Keiser: The Family, Infant, and Toddler Program (FITP) also serves quite a few children on the autism spectrum who have high needs. Recommends that Jane Ross Allen be on the workgroup.
- Unruh: Will have to guard against high staff turnover due to low salaries, isolation in the community, and lack of support structure for the staff.
- Gold: Supports organizing and activating a small but knowledgeable group. Wants a connection to transition age youth, including young adults who just miss being officially on the spectrum. He deeply respects the demands on the DS system; it cannot just shift away from its commitments to people to take on a new task. Recommends a member from the New Agency Team be on the workgroup.

III. Input

Guy began this segment by expressing the Board's appreciation of the new level of interagency collaboration evident under the expanded DOE/AHS Interagency Agreement. Major points of input include the following.

Cate:

- Evidence of strengthing coordination under Act 264 and the Interagency Agreement:
  - Answering questions from the May 1st kickoff event
  - LITs are receiving more training
  - Implementation Committee meets monthly; established committees for evaluation and for forms
  - SIT continues in expanded format
  - BEST is contributing resources

- *Interagency Matters* newsletter will be coming out
- Emerging priority is autism and the need for a Vermont model to respond in a more coordinated, systematic manner to the needs of children and their families

Johnson:

- Field Service Directors are all active on the LITs and share direct responsibility with the education representatives to assure optimal functioning
- Will connect with the evaluation team to assure that good data goes out to the LITs.
- Reported conversations about using the LIT model for adults, especially if LITS are working increasingly with the adult system around youth transitioning to adult life.

Moffatt:

- Key areas for VDH/DMH are early intervention and transition to adult life. Sees need to develop best practices and get services in place. Also sees issues for minority health; we need to get upstream with minority youth.
- Urges this Board to be bold and advocate that mental health stay within VDH; believes that children's mental health will lose out if pulled away. Wants to work with the Board to resolve questions on this issue.
- Recent helpful grants to VDH include:
  - Co-occurring
  - Co-sig: $1.1 million for 3 years and then decrease over 5 years. Purpose is to integrate substance abuse, mental health, and physical health. Recently hired Coordinator: Paul Dragon.

Wood:

- DS is now an active member of SIT on both cases and policy. Progress in participation at the local level is developing in pockets; HCHS is a great model. The state level is trying to encourage and support local providers to engage; historically there is a perception of being barriers rather than resources for each other. Contracted providers in particular got a lot out of the May 1st kickoff event. LITs should tell local and state DS if they want more participation.
- Asked the Board to share with the state any data it gathers on who is and is not now using the expanded system. Jo-Anne noted that the Evaluation Group will have its first meeting on September 20; they want to gather data at the Individual Treatment Team, LIT, and SIT levels.

Gold:

- Reported substantial progress on the trauma priority from 2006 with AHS Trauma Coordinator Sherry Burnette. She will become the co-chair of the Governor's Council on Domestic Violence. She has developed training curricula for various groups to increase trauma awareness and would like to do a training for LITs. Steve will give Alice a copy of the curriculum developed for a training of staff at Woodside to share with the Board.
- Global Commitment (GC) presents us with opportunities and challenges. There is a lot of Medicaid funding in children's services. GC has a 5-year overall cap and a cap for each of the 5 years. We do not yet know what the financial implications are for the developing Catamount Health premium assistance plan or its implications on the pre-existing GC. On the plus side, GC is essentially an investment opportunity; it will allow Vermont to capitalize on flexibility to help bend the curve on rapidly rising long-term health care costs. Other states have not been offered this much of an opportunity, and we have a limited time to demonstrate its worth. Therefore, the state is being cautious about any financial commitments at this time. Suzanne Santarcangelo is the point person to oversee GC. Various committees have been formed; one is to review any potentially great new ideas that could bend the curve. We hope to have a better idea about cost implications within one year.

Jeff noted current inequities in the distribution of Medicaid funds. Steve said that AHS is not committed to resolving any inequities at this time, but will look into such situations as it can.

Keiser:

- Reported that DCF is working to align DOE and AHS initiatives. They are seeing a broader use of Coordinated Service Plans (CSPs). The Child Development Division is currently strategizing (not yet implementing) how to best integrate 3 programs: FITP, CUPS, and Healthy Babies, Kids, and Families.

Flood:

- Reported on the Transition Task Force; Vocational Rehabilitation (VR) has just released its white paper. AHS Secretary Cindy LaWare wants a transition approach for all youth, not just youth leaving state's custody. VR may lead this work. He will forward the white paper to Alice for distribution.
- A priority for the coming year is moving forward with the JOBS initiative. Wants increased flexibility on how agencies use the funds. The Board may get further information about this from Diane Dalmasse.

Johnson:

- There have been 4 major groups working on transition in the last year: Justice for Children; Post Secondary Education; VR; and DCF. The September meeting of the State Team will launch its second initiative and it will be on transition age youth. There will be data available from the initial presentation.

Keiser:

- DCF will publicly release its report for the legislature on transition in a few weeks; it is entitled *Hope for the Future*.